

CLIENT ACTION BULLETIN

May 23, 2008

CAB 08-12

New Genetic Information Nondiscrimination Law

SUMMARY The "Genetic Information Nondiscrimination Act of 2008" (GINA, P.L.110-233), which the President signed on May 21, prohibits employers, health plan sponsors, and health insurers from discriminating on the basis of individuals' (and their family members') genetic information. For employers, the law covers genetic nondiscrimination in group health plans and employment practices, generally extending the privacy protections available under the Health Insurance Portability and Accountability Act (HIPAA) and the prohibitions on employment discrimination under the Title VII of the 1964 Civil Rights Act and other similar laws.

GINA, which becomes effective May 8, 2009 (for the health plan-related provisions), and November 8, 2009 (for the employment-related provisions), does not preempt state laws that are more protective of individuals.

DISCUSSION **Unlawful Group Health Plan Practices**

By amending the Employee Retirement Income Security Act (ERISA), the Public Health Service Act (PHSA), and the Internal Revenue Code, GINA applies to all group health plans and insurance, including state regulated health plans and nonfederal governmental plans. The new law prohibits plans and insurers from:

- imposing enrollment restrictions and premium adjustments on the basis of genetic information or genetic services;
- requiring employee contributions to differ on the basis of genetic information; or
- requesting or requiring that an individual take a genetic test (although a healthcare professional is permitted to request an individual to undergo a genetic test).

GINA's definition of "genetic information" covers information about an individual's or his/her family members' genetic tests, diseases, and disorders. It also includes any request for or receipt of genetic services by an individual or family members, but does not include information about the age or sex of an individual. Genetic information concerning an individual or family member extends to both a fetus carried by a pregnant woman or an embryo legally held by an individual or family member using assisted reproductive technology. "Genetic test" means an analysis of human DNA, RNA, chromosomes, proteins, or metabolites that detects genotypes, mutations, or chromosomal changes; "genetic services" include genetic counseling or genetic education.

A group health plan is allowed to obtain or use the results of a genetic test to determine payment for treatments and services, but may only request the minimum amount of information needed to do so and must handle the information as HIPAA-protected information. Genetic information possessed by employers – whether for payment purposes or inadvertently obtained – must be confidentially maintained and disclosed only under tightly controlled circumstances.

A group health plan may request, but not require, a participant or beneficiary to undergo a genetic test for research purposes, but only if certain requirements are met. The plan must clearly indicate that compliance is voluntary and noncompliance will have no effect on enrollment status or premium or contribution amounts. No genetic information collected or acquired may be used for underwriting purposes. Moreover, the plan must inform the Secretary of Health and Human Services about the research activities being conducted pursuant to this exception.

Unlawful Employment Practices

GINA's provisions relating to employment practices prohibit discrimination on the basis of genetic information in hiring, compensation, and other personnel processes; forbid the collection of

genetic information; and allow genetic testing only in very limited circumstances, such as monitoring the adverse effects of hazardous workplace exposures. “Genetic information” is defined as under the health plan/insurance provisions but also clarifies that medical information on manifested diseases and illnesses is not genetic information. The law applies to employers, employment agencies, labor organizations, and joint labor-management committees, with similar restrictions on employment practices applying to the different covered entities.

Specific unlawful practices include failing to hire, train, or retrain someone or discharging or otherwise discriminating against an employee with respect to the compensation, terms, conditions, or privileges of their employment. GINA also prohibits an employer from limiting, segregating, or classifying employees or individuals because of genetic information in any way that would deprive (or tend to deprive) them of employment opportunities or otherwise adversely affect their status as employees.

Employers may not disclose genetic information they possess, except:

- to the employee or member upon request;
- to an occupational safety or other health researcher;
- in response to a court order;
- to government officials investigating GINA compliance;
- in connection with the employer’s compliance with the medical certification provisions of the federal Family and Medical Leave Act or similar state laws; or
- to a public health agency.

GINA imposes limits on acquiring genetic information. For example, an employer may acquire genetic information about an individual to monitor the biological effects of toxic substances in the workplace. An employer also may provide genetic services (including through wellness programs), but only if the employee supplies written authorization and the individualized results are not disclosed to the employer.

Remedies and Enforcement

GINA establishes different mechanisms to enforce the law. For violations of the law’s requirements on health plans and insurance, ERISA and PHS (along with civil penalties under the tax code and HIPAA) apply. GINA amends ERISA and PHS to allow the Labor Secretary or the Health and Human Services Secretary, respectively, to impose penalties of \$100 per day of noncompliance for each participant or beneficiary to whom a failure relates, while also establishing minimum and maximum penalties (including prison terms for violations committed for commercial advantage, personal gain, or malicious harm). Violations under GINA’s employment practices provisions are addressed by the civil rights’ laws, which include individual suits, jury trials, and compensatory and punitive damages.

ACTION Employers, employment agencies, labor organizations, joint labor-management committees, and group health plan sponsors and insurers should become familiar with GINA’s new requirements and take necessary steps to ensure that any genetic information about an employee be treated with strict confidentiality, as with other personal medical information under HIPAA. And although the law is effective in the future and definitive regulations will not be issued for a year, employers can act now toward compliance by applying the HIPAA rules to genetic information.

Some employers will have to confront the lack of a complete federal override of various state requirements. In addition, GINA’s “common sense” approach is likely to be tested in actual practice, requiring employers to await clear definitions and examples in regulations to be issued. Employers, health plan sponsors, and others should seek the advice of counsel with regard to applying the new law’s requirements on genetic nondiscrimination in health plans and insurance, as well as with regard to restrictions on employment practices.

For more information about GINA, please contact your Milliman consultant.